

NEW YORK STATE RARE DISEASE WORKGROUP
AGENDA
September 26, 2023
11am-1pm

- 1. Welcome by Workgroup Co-Chairs** *5 minutes*
Melissa Pittel Wasserstein
Chief, Division of Pediatric Genetic Medicine
Children's Hospital at Montefiore

Mary Wootten
Member Coordinator, The Oley Foundation
Volunteer, New York Rare Action Network Ambassador, NORD
- 2. Access to Care and Referrals: Report out and Discussion** *30 minutes*
Mary Wootten
- 3. Patient and Caregiver Support: Report out and Discussion** *30 minutes*
Bob Graham
Patient & Public Policy Director
New York State Bleeding Disorders Coalition
- 4. NORD Policy and Program Priorities** *30 minutes*
Carolyn Sheridan
State Policy Manager
National Organization for Rare Disorders
- 5. Open Discussion** *15 minutes*
All members led by Co-Chairs
- 6. Closing** *5 minutes*
Melissa Pittel Wasserstein, Co-Chair
Mary Wootten, Co-Chair
Barb Wallace, NYSDOH